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A QUALITATIVE STUDY OF THE PERCEIVED VALUE OF MEMBERSHIP IN
THE OLEY FOUNDATION BY HOME PARENTERAL AND ENTERAL
NUTRITION CONSUMERS

BY KATELYN CHOPY

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE IN
NUTRITION AND FOOD SCIENCE

UNIVERSITY OF RHODE ISLAND

2013

MASTER OF SCIENCE THESIS

OF

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2013

Abstract

Background: Support and educational organizations have been shown to improve quality of life in consumers of home parenteral nutrition (HPN) and home enteral nutrition (HEN). One such organization, The Oley Foundation, offers resources for the home parenteral and enteral nutrition (HPEN) consumer. Research has shown that the Oley Foundation has lead to positive outcomes for members. No studies have determined what services consumers value, how they were introduced to the organization, and how this impacted them individually. This study used qualitative methodology to gain a deeper understanding of the perceived value of membership in the Oley Foundation for HPEN consumers. The research questions this study answered were:

1. What is the value of membership in the Oley Foundation to HPEN consumers and why do they perceive this as valuable?
2. At what point do consumers learn about The Oley Foundation and how are they introduced?
3. What similarities and differences are there between home parenteral nutrition consumers and home enteral nutrition consumers concerning experiences with The Oley Foundation?

Participants: The participants in this study included 13 adults who were depended on HEN (n=6), HPN (n=6), or both HEN and HPN (n=1) and had joined the Oley Foundation within the last two years.

Methods: An investigator conducted audio-taped, one-on-one, in-depth telephone interviews guided by an interview template that included: all elements of informed

consent, approval to audio-tape, biographical and demographic information and questions designed to allow for the expression of participants' experiences, opinions and feelings as a member of The Oley Foundation. Each interview was summarized, reviewed by a committee member, and sent to the participant. An investigator conducted follow up interviews to ensure accuracy and illuminate any nuances overlooked or misinterpreted by the interviewer. Content analysis was used to code and group segments of text to identify themes. Emergent themes were used to answer the research questions and develop a model to conceptualize the value members perceive in membership to the Oley Foundation.

Results: The results of this study suggest that the value of the Oley Foundation lies in programs and resources provided and the competency, inspiration, normalcy, and advocacy gained from membership. In this study participants were introduced at a variety of points in time. More than half of participants found the organization on their own. A clear theme that emerged from the discussion of participant's introduction to organization was "I wish I knew about it sooner". While HPN and HEN consumers were quite similar they differed in the concerns they had about drug shortages and insurance coverage, respectively.

Discussion and Conclusion: This study showed that value in the Oley Foundation is based on the competency, inspiration, normalcy, and advocacy membership creates. An emergent theme, "I wish I would have known about it sooner" underscores the need for educating home parenteral and enteral nutrition consumers about organizations like the Oley Foundation

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Preface

This thesis was written to comply with the University of Rhode Island Graduate School Manuscript Thesis Format. This thesis contains one manuscript entitled “A Qualitative Study of the Perceived Value of Membership in the Oley Foundation by Home Parenteral and Enteral Nutrition Consumers”. This manuscript has been written in a form suitable for publication in the Journal of Parenteral and Enteral Nutrition.

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A QUALITATIVE STUDY OF THE PERCEIVED VALUE OF MEMBERSHIP IN
THE OLEY FOUNDATION BY HOME PARENTERAL AND ENTERAL
NUTRITION CONSUMERS

By

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is prepared for submission to the Journal of Parenteral and Enteral Nutrition

Clinical Relevancy Statement

This study showed that value in the Oley Foundation is based on the programs and resources provided and the competency, inspiration, normalcy, and advocacy membership creates. An emergent theme, “I wish I would have known about it sooner” underscores the need for educating home parenteral and enteral nutrition consumers about organizations like the Oley Foundation.

Introduction

Background

Home nutrition support is a long-term therapy that provides nutrition intravenously (parenterally) or through the gastrointestinal tract (enterally) when a person is unable to consume or digest enough food to maintain or restore nutrition status and health. Home parenteral nutrition (HPN) involves intravenous infusion of nutrients through a central venous catheter for people who are unable to digest/absorb nutrients through the gastrointestinal tract. Home enteral nutrition (HEN) involves the provision of nutrients through a nasogastric tube or a percutaneous or surgically placed tube in either the stomach or the small intestine. Although there are no complete databases of home parenteral and enteral nutrition consumers, the American Society of Parenteral and Enteral Nutrition estimates that there are approximately 73,000 HEN consumers and 39,000 HPN consumers in the US ^{1,2}. While the ability to provide nutrition through alternate routes is a life-saving therapy, it is not without its complications. Consumers of home parenteral and enteral nutrition (HPEN) have many physical and psycho-social factors influencing their quality of life.

Physical complications such as mechanical problems with equipment, infections, and intolerance issues impact consumers of HPEN^{3,4}. Psycho-social factors include coping with medical diagnoses, being dependent on technology, the loss of the eating experience, reliance on others for care, low self-esteem, interference with sexual function and the financial burden of nutrition support. All of these present a challenge to the HPEN consumer^{4,5}. While factors make life difficult for the HPEN consumer there are resources available to help cope with these obstacles.

The Oley Foundation is a non-profit organization that provides up to date educational materials and social support for consumers of HPEN at no cost. The organization was founded in 1983 by Dr. Lyn Howard and Clarence Oldenberg, a HPN patient, in order to share information and support throughout the HPEN community. The Oley Foundation currently has 12,500 members including clinicians and family of HPEN consumers. Educational topics include; current research, management of HPEN related complications, and practical topics such as travel tips. Oley provides social support through a toll free hot-line, social media groups on Inspire.com and Facebook, support group coordination, and regional and national conferences. By “informing, connecting and supporting,” Oley hopes to improve quality of life for all consumers of HEN and HPN⁵.

Statement of the Problem

Those receiving HPN and HEN face many physical and psychological challenges in coping with their disease state as well as challenges in their continual reliance on nutrition support (due to its nature as a high-risk and technologically sophisticated therapy). Support and educational organizations have been shown to

improve quality of life in consumers of (HPN) and (HEN), but little is known about the perceived value of these services by the consumer ^{4,6,7}.

Organizations aimed at providing information and social support, such as the Oley Foundation, are available to offer resources that can help to improve quality of life for the home parenteral and enteral nutrition (HPEN) consumer. No studies have determined what services are valued by consumers and how their introduction to the organization impacted them individually.

This study used in-depth interviewing to gain a greater understanding of the perceived value of membership in the Oley Foundation with a goal of improving the provision of services to members.

Methods

Research Design

This study utilized qualitative techniques to explore how HPEN consumers perceive the way in which they were introduced to the Oley Foundation and what programs, services, or intangible benefits they perceive as impacting them the most. Qualitative methodology was appropriate because the research aim was to understand participant involvement in the organization in an uncontrolled context specific setting⁸. Interviews were used to elucidate perceptions and emotions participants have toward their involvement with The Oley Foundation and their experiences with HPEN⁹.

Thirteen participants took part in audio-recorded semi-structured telephone interviews. Interviews allowed for a clear representation of the phenomena and avoidance of biased responses by having participants speak openly on topics. Grand tour questions such as, “Could you describe your involvement with The Oley Foundation” prompted the participant to give a verbal tour of their relevant experiences. Prompts such as, “how were you introduced to the organization?” clarified and maximized participant response¹⁰. Recordings of each interview were transcribed verbatim, de-identified and saved as word documents. Data were, coded, interpreted, and analyzed using Nvivo software (QSR International PTY Ltd, 2012 Melbourne, Australia). Words, phrases, and segments of text were coded and grouped together to identify similar passages and themes such as attitudes, behaviors, motivations and views about The Oley Foundation. Similarities and differences

between HPN and HEN consumers were further explored. The interviews took place February-May 2013, data analysis was ongoing.

The Institutional Review Boards of Rhode Island Hospital and The University of Rhode Island as well as the research committee of the Oley Foundation approved all procedures and materials. Recruitment materials can be found in Appendix C.

Sampling

This study used a purposive homogenous sampling method to recruit participants¹⁰. Recruitment statements included the purpose of the study, eligibility criteria, and the study email address (oleystudy@etal.uri.edu). Announcements were made on The Oley Foundation's website and emails sent by The Oley Foundation to members who had joined in the past two years.

Study candidates self-selected to participate by contacting the study's e-mail address. An initial phone call was used to screen participants and to schedule an interview. Inclusion criteria included English-speaking adults over the age of 18 who were dependent on home parenteral or enteral nutrition and have joined The Oley Foundation in the past two years. Exclusion criteria were pregnant women and anyone not meeting inclusion criteria. The criterion that the participants had joined The Oley Foundation within the past two years was set so that participants would better recall their introductions to the Oley Foundation.

Twenty-two members responded and 13 were selected to participate. The chosen sample included 6 HPN, 6 HEN and 1 HPEN consumer. Equal groups were chosen so that the groups could be analyzed for similarities and differences. 2

participants were not included in the study because they were family of HPEN dependent members and 7 participants were not included because data saturation had been met, as no new themes were emerging from the data. One participant dropped out because of medical complications.

Sample size was determined based on previous qualitative studies using in-depth interviews with HPEN consumers^{6,7,11}. Groups of equal size were selected in order to be able to explore similarities and differences between parenteral and enteral nutrition consumers' experiences. Data saturation was met after thirteen interviews as similar themes were emerging from all interviews.

Data Collection

Participants scheduled 60 minute appointments for semi-structured telephone interviews. The interviews were conducted in an investigator's office at Rhode Island Hospital. The interview questions were developed and revised after an extensive review of the literature and were reviewed by committee members with expertise in qualitative research and experience with HPEN consumers. A pilot interview was conducted with a volunteer Oley Foundation member to evaluate the purpose, intent and clarity of each question. The data from this pilot interview were not included in the results of the study.

As outlined in the interview guide, participants gave verbal informed consent by telephone to participate in the study. Three "grand tour" questions were asked about their experience with HPEN, their involvement in Oley, and recommendations for new consumers of HPEN and clinicians. The grand tour questions prompted the

participants to give a verbal summation of their experiences in order to uncover common themes of what has been valuable to them ¹⁰. The questions included a series of probes designed to clarify and maximize participant responses. In-depth telephone interviews such as these have been previously used to document experiences in this population, and would be appropriate to explore the meaning of membership in The Oley Foundation ^{4,7}. An advantage of telephone interviews is confidentiality for participants, allowing them to speak freely and honestly. Disadvantages are that participants may be more likely to answer briefly, and body language and nonverbal cues are lost ¹². The probes described above allowed the investigator to delve further into how membership in The Oley Foundation affects participants' experiences. The interviewer kept detailed notes on impression, voice and intonation.

Demographic information was collected prior to concluding each interview if not previously disclosed and included: type of nutrition support therapy, medical diagnosis, length of time dependent on HEN or HPN, age, gender identification, number of people in the household, geographic location, employment status, school enrollment and highest education level achieved.

Each telephone interview was tape-recorded in a private setting. Detailed notes were taken during the interview concerning impression, subtle cues, apparent confusion about questions etc. One study investigator (KC) conducted and transcribed each interview and uploaded transcripts into NVivo Software (QSR International PTY Ltd, 2012 Melbourne, Australia) to assist in organization of data. Theoretical notes were taken about the overall impression of the interview and general themes and were used to assist the data analysis. Methodological notes were taken concerning any

changes that should be made in future interviews. A summary of each interview was written and sent to each participant to confirm findings and to ensure the investigator interpreted the response correctly.

Data Analysis

Meaning was derived from the data through inductive content analysis. This analysis is based on the development of categories designed to capture the dominant themes from each interview¹³. This method of analysis allowed for a condensed description of the phenomena, value of membership in the Oley Foundation¹⁴. A phenomenological approach allowed for the interpretation and description of how consumers perceive their membership in The Oley Foundation⁷. Transcripts were read several times and analyzed with an open coding scheme in which words and phrases were organized into groups and categorized in order to identify similar concepts and emerging themes and an illustration was developed (Figure 1) to conceptualize the value of membership in the Oley Foundation¹⁴. Quotations pertaining to each theme and research question are found in the Results and Discussion sections.

Validity and Reliability

Trustworthiness and credibility of the data were established by seeking negative or contradictory examples with probes and by providing supporting examples for conclusions drawn, i.e. direct quotations¹². Five interviews were coded by two study investigators; substantial inter-coder agreement was established with a Cohen's

Kappa co-efficient of 0.842¹⁵. The kappa co-efficient was calculated using SPSS Version 20 (IBM, 2011, Armonk, NY). Based on the high level of agreement determined by the kappa co-efficient the remaining interviews were coded by a single investigator. A written summary of each transcript was reviewed by a committee member and emailed to each participant as an initial member check and was discussed during the follow-up call. A member check allows the participant to review the data provided by their interview to ensure accuracy and to illuminate any nuances overlooked or misinterpreted by the interviewer¹³.

Follow up calls were conducted with 8 out of 13 participants. All participants supported the interpretation in the summaries; some made a few clarifications and emphasized the importance of topics they discussed during the interviews. Highest level of education was a demographic that was added after several interviews so this demographic was obtained during the follow up calls if needed. New information was brought up regarding change in nutrition therapy but these data were not included in the final analysis.

Demographics

Microsoft Office Excel (2007) was used for descriptive statistical analysis (mean and frequency) of demographic data including age, gender identification, marital status, number of people in the household, geographic location, employment/education status, highest level of education, medical diagnosis, type of nutrition support, and length of time dependent on HEN or HPN.

Results

The aim of this study was to gain a greater understanding of the perceived value of membership in the Oley Foundation, an education, outreach, and networking organization for consumers of HPEN. The research questions this study answered were:

1. What is the value of membership in the Oley Foundation to HPEN consumers and why do they perceive this as valuable?
2. At what point do consumers learn about The Oley Foundation and how are they introduced?
3. What similarities and differences are there between home parenteral nutrition consumers and home enteral nutrition consumers concerning experiences with The Oley Foundation?

The following sections will provide a description of the study population, contain the analysis of the data as they relate to the study aim and research questions, and introduce additional themes that emerged during this data analysis. Quotes describe participants' perceptions of the value of the Oley Foundation and their introduction to the organization as well as exemplify similarities and differences between groups. Ellipses were used to signify missing words in quotes such as "you know" or "ums". Categories and themes were labeled using participants' words as well as the investigator's interpretation of the interview data.

Description of Study Participants

A total of 22 participants responded to recruitment emails sent out by the Oley Foundation. Thirteen respondents were selected to participate in the study (59%). Reasons for exclusion were the participant was not dependent on HEN or HPN and data saturation occurred.

The average length of time of the interviews was 29 ± 9.6 minutes (range=16-47 minutes). Characteristics of the study sample are shown in Table 1.

Table 1: Demographic Characteristics of Study Participants	
Type of Nutrition Therapy	Home Enteral Nutrition (n=6) Home Parenteral Nutrition (n=6) Home Parenteral and Enteral Nutrition (n=1)
Years on HPEN	6.9 ± 9.9 (range: 0.75-31)
Gender (% Female)	62.00%
Race (% Caucasian)	92.00%
Age (years)	38 ± 11.9 (range: 22-61)
Percent Employed	38.00%
Percent Enrolled in School	15.30%
Number of People in the Home	1.8 ± 1.5 (range: 0-5)
Highest Level of Education *	Some College (n=2) Associate's Degree (n=1) Bachelor's Degree (n=6) Master's Degree (n=1) Doctoral Degree (n=1)
Geographic Location	Maine (n=1) Ohio (n=4) Virginia (n=1) New York (n=2) Massachusetts (n=1) Florida (n=1) Utah (n=1) New Jersey (n=1) Iowa (n=1)
Medical Diagnosis	Gastroparesis (n=4) Parkinson's Plus Syndrome(n=1) Amyotrophic lateral sclerosis (ALS) (n=1) Gastrointestinal dysmotility (n=2) Crohn's Disease (n=1) Intestinal Failure (n=2) Chronic Intestinal Pseudo Obstruction (n=2)

* Highest level of education not reported for two participants.

Data Analysis

The concept of value of membership in the Oley Foundation that emerged from the analysis can be categorized into programs and resources provided by the Oley Foundation and the themes of competency, inspiration, normalcy and advocacy. The programs and resources described as valuable were: newsletters, educational materials, regular emails, restaurant cards, social support, social media sites, the supply exchange and the conferences. Table 2 outlines the themes and specific related categories that were developed based on analysis of repeated concepts throughout the interviews.

Table 2: Themes Relating to the Value of the Oley Foundation	
Theme	Categories
Competency	Providing Tools to Manage Care Making Personal Medical Decisions The Consumer as an Educator
Inspiration	Sharing Experiences Seeing that Others Can Do It
Normalcy	Sense of Community Helping Others I am Not Alone HPEN Does Not Need to Impede Life
Advocacy	Oley as a Consumer Advocate

Programs and Resources

The Oley Foundation provides a wide range of programs and resources that were described as helpful, important or valuable including: newsletters, educational materials, regular emails, restaurant cards, social media sites (Inspire or Facebook), and social support (e.g. support groups or telephone contact information for people with similar diagnoses or nutrition therapy), the supply exchange and the conferences. Representative quotes describing participant perceptions of or experiences with different programs and resources are shown in Table 3.

While there was a range of programs and services used (from only reading the newsletter to using all programs and resources), most people read the newsletter, educational materials and viewed the Inspire site. While none of the participants had attended a conference, several talked about them as a valuable programs and expressed hope to one day attend. For example one participant stated, “I look at the conferences and as soon as they have one within my area I would like to attend.”

Some participants were very involved in social media/ support sites (Inspire and Facebook), while others passively monitored them or did not use them at all.

One female HEN participant explained that she is mainly interested in resources and educational materials, “basically I don't have a lot of personal involvement. I have looked to them, online, for resources and stuff like that. To learn more about my tube feeding basically.”

Table 3: Programs and Resources Valued

Newsletter

"they have articles, they have a bimonthly newsletter . . . where you get to see that you're not the only person that has this problem."

Educational Materials

"..the educational materials: how to clean your feeding tube, how to take care of it, little tricks , gimmicks that you can use to . . . have a better life with your feeding tube"

Emails

"The emails they send out and I kind of get excited every time I get an email from them. I know that sounds corny but it's something that kind of helps me through the process more or less. "

Restaurant Cards

"they sent me some cards that I can carry with me so that when I go out in public with my family to a restaurant or whatever I can give the waitress a card and let them know that I'm not eating and why I'm not eating"

Social Media

"It's been really helpful getting information and knowing that other people are on tube feeds as well. I mean I've never personally met anyone else on tube feeds but . . . just. . . getting information through the forum "

Social Support

"And then also as a network. To meet other people who tube feed and . . . when I found out that I might be switching from a tube to a central line . . . there were other people from Oley Foundation who I could call and meet people who have a central line and see what life's like with that "

Supply Exchange

"I know I've said this like a billion times but the supply exchange that's helped me because I was going on a formula trial with different things and my supply company they would only send me like a couple to try."

"I had this formula but I couldn't send it back so . . . I was able to send it to people that needed it, who didn't have insurance coverage."

Conferences

"I'll be a part of, I'll be hearing things, and just being, and just being able to go and seeing all these people with backpacks and tubes coming out and things like that and not having the oh why'd you wear that.. it's not a bunch of weird people. It's not someone wearing a backpack in the middle of the day with tubes coming out of it. It's kind of a just a normal thing and to meet different people and the supply companies and stuff like that.. it's just going to be a great resource."

Competency

Several participants described a feeling of competence, that they had adequate knowledge, skills or experience to manage their lives on HPEN. This feeling of competence was discussed in three different capacities; Oley providing tools to manage care, Oley helping the participant to make personal medical decisions, and the consumer as an educator.

Tools to Manage Care and Solve Problems

One male HEN participant who did not receive any discharge education describes how he and his family used the Oley Foundation to educate themselves:

We literally did a crash course on Oley that night, my family, my wife and my brother, they all each got on there, My brother was on his laptop, my wife was over on my computer and they literally was reading stuff on how to flush it. So Oley, if it wasn't for Oley that first night I would have never, we wouldn't we wouldn't have known what to do.

One female HEN participant explains:

And also it gives me a sense of, I don't know, almost like a more of a competency that there are things that I can learn more. It's hard to find resources specific to tube feeding . . . I have the basic stuff from the company that manufactures the tube and I had very very basic stuff from the doctors but a lot of what I find is specific to a G-tube and mine's a J-tube so there are pumping instructions that are different. And you can't just change your own J-tube you have to have it changed in interventional radiology and stuff like that and I found Oley just the information they provide has helped me gain a lot of

knowledge and less fear about having the tube or even having complications when they do arise

In describing problem solving several participants stated that getting information from their peers was beneficial.

The doctors that I have anyways are wonderful but there are times where they too are baffled by drainage or . . . don't always have the answer to a question and sometimes what I like about Oley is how it can pull together kind of the wisdom of just the common folk who've experienced the tube and just kind of like what works what doesn't

Helping Participants Make Informed Medical Decisions

One female HPN participant was able to make an informed decision about a new drug after reading information on the Oley Website.

I learned about it [the drug] and then about two weeks ago one of my doctors had brought it up and since I had read up on it on the Oley Foundation I was informed on it, because of my situation I was a candidate. So it looks like I'm going to be on it.

Another male HPN participant commented on the same drug information stating,

Well there was, well obviously you can find information, well obviously information is published on medications in academic journals, this was a summary of the drug trials by the company that's producing the medication and I believe the article was written by one of the lead researchers for the medication. And it was technical enough to be helpful and simple enough to be understandable by me, and I assume most of the population that reads the Oley

publications and so it is useful for getting a simple yet complete profile of the medication.

The Consumer as an Educator

Some participants discussed sharing information from the Oley Foundation with others. For example one female participant stated, “it’s kept me informed to where . . . it helps me better understand a lot of stuff, to where I can explain it to my kids.” Other participants commented on sending friends and family information from the Oley Foundation.

And I send my friends and family to Oley all the time and none of them have tubes or central lines. But they have so many resources that help having them reading helps them understand different things that I’m explaining it or sometimes Oley can explain it a lot better than I can

Two participants discussed being able to use the Oley Foundation to educate their clinicians who were unfamiliar with HEN:

Male HEN consumer

We actually, I got with his nurse and hooked them with the Oley Foundation and printed off the educational materials and so they actually made a binder for feeding tubes, kind of like a check list of what they need to do next time somebody gets a feeding tube that’s not in home health. And 100% of that information came from the Oley Foundation.

Female HEN consumer

I don’t get seen . . . in a major city area so the doctors aren’t always familiar with tubes and things like that. So . . . I basically did a bunch of research on

different types of tubes and brought that information to the surgeon who contacted the rep from the company who came and met with us to figure out what kind of tube would be best and things like that. So . . . just becoming... learning as much as you can but not over doing it.

Inspiration

Most participants described how Oley inspired or encouraged them to live their lives. They were inspired by sharing experiences and information and seeing that other people can succeed.

Sharing Experiences with Others

One participant was initially reluctant to consent to placement of a feeding tube because as he stated, “at first I thought the feeding tube was the end of life and something that old people get right before they die and I was only, well I was 40 when I got the feeding tube.” He described that he was inspired to make his decision to get a feeding tube:

Because of the information I got on the Oley Foundation website and . . .because of that information I went and consented to the feeding tube and it actually has enhanced my life. . . just the fact that other people was living, LIVING life with their feeding tubes was a mainstay, it helped me make my determination.

Two participants stated that the stories about children on feeding tubes were encouraging to them. One participant stated laughingly:

The babies, so many small kids, I figured if these kindergarten people can these kindergarten aged people can go to kindergarten with their feeding tubes and

with their backpacks with their feeding pumps, surely a grown man who was in the army could tackle it too.

Seeing that Others Can Do It

Seeing other people succeed was a source of inspiration for many participants. One woman described how reading positive stories helped change her attitude towards her feeding tube:

I just think that they've helped me . . . there's certain things that come to us in life and we can, they're going to be with us whether we want them or not and I think that Oley has helped with my attitude towards the tube really. That I can bemoan it and be poor little me and . . . people will be . . . oh poor you . . . most people don't even know I have it because I just go about life with it. It's normal for me now and I think Oley helped a lot with that attitude.

When asked if the Oley Foundation had influenced her experience with HEN one participant stated, "Oley made it something less fearful." This sentiment is supported when another participant described how information that he got from Oley helped him make his decision to get a feeding tube less fearful.

So they provided me the initial information that helped me go ahead and say "Ok this isn't the end of life decision, this is something that kids and old people and young people get and they can carry on a decent life as long as their disability allows.

Normalcy

A common theme throughout the interviews was that membership in the Oley Foundation provided a sense of normalcy. Different aspects of this theme included a

sense of community, a feeling that there are other people like them, and the realization that HPEN doesn't need to impede daily life.

Sense of Community

Some participants expressed a feeling of camaraderie gained from Oley by giving them a way to communicate with other members.

I mean I think more than anything it does show you, I mean it is a support network and it does show you that there are a lot of other people that may be going through the same or similar things that we would have never known where anyone else was . . . So I think that it's just that it's there, learning about, and learning about all those that have had to live with artificial nutrition, and . . . are thriving. I think that's probably one of the best things that it does

Helping others

A sense of altruism within the community is demonstrated when several participants spoke about the organization providing them with an opportunity to help others, for example by participating in research studies. One participant discussed this by stating, "the other big thing for me is the opportunities. Whether it be research oriented or whatever. To know that I can, this is going to help not just me but other people is important to me as well."

Another participant commented on how members want to help one another:

It's just a group of people that have . . . either similar or identical situations that are there and provide feedback of how they've done things and how they're dealing with things. It's just more of a community of people that want to be there to help.

I am not alone

Table 4 contains quotes that describe participants gaining a sense of normalcy from the knowledge that there are other people in similar situations.

Table 4: Representative Quotations Expressing the Sentiment “I am not alone”
<p>It’s helped me not feel so isolated or alone. Like I’m not the only one that certain things have happened to . . . if I felt like I was the only one in the world dealing with this it would have been much harder. And initially I did definitely feel like that.</p> <p>Because before I didn't have, there was nobody, there was no support group for me, there's no one around me. Everybody here where I live they've never seen this before. So to be able to gravitate towards a group of people that kind of, are there for people who really don't have anywhere to go more or less.</p> <p>It basically makes me feel like I'm not the only one.</p> <p>I try to make life normal. We talk about normal school things . . . I don’t want to discuss feedings with them or walking around with tube feeds or . . . if my stomach is weird or any of that stuff. So it’s nice to have kind of a I guess an outlet to discuss that with. And knowing that other people my age dealing with that.</p> <p>They basically show you that there are people all over the world. We’re not just talking about here in the States. I talk to people all the way in Australia that have dealt with stuff like this. That, that right there, is just that added confirmation and that added reassurance that you are not the only one out there you are not just, just because you live here in the United States that you’re the only person that’s there.</p>

HPEN Doesn’t Need to Impede Life

Some participants had the perception before joining Oley that HPEN would prevent them from living normal lives. A male HEN participant describes how Oley showed him healthy people can have feeding tubes too:

I didn't realize how many hundreds of thousands of people every year get a feeding tube and many just for 6 months or a year and some get it for 20, 30, 40 years. Children get them from the time they're born to the time they pass away when they're 80 or 90 years old. I didn't realize that , I just thought it was old people in the nursing home whose family didn't want to let them go. God . . . I didn't realize healthy people with disabilities or health problems get them to have lives

A female HEN participant describes how the Foundation has helped her to change her attitude and live life normally with her tube, "most people don't even know I have it [J-Tube] because I just go about life with it. It's normal for me now and I think Oley helped a lot with that attitude."

Advocacy

Oley as a Consumer Advocate

Several participants discussed the Oley Foundation as a consumer advocate. Two participants talked about how there is no "American Heart Association or American Cancer Society" for people who are dependent on HPEN. Having a group that advocated for them was very important.

The biggest thing, I mean I don't think you can say anything bad about the way that they... they are patient advocates. That's really the first thing I would tell someone, you really ought to look this organization up. There are some organizations that more or less are there for the money. The Oley Foundation is really there for the patient and that's something that you don't see. If some says hey what do you think about, maybe they say my stomach's not working,

the first thing I would say to them is join the Oley Foundation. They are there for the patients; everything that they do is for the patient. Whether it's information on recalls, or a drug, or opportunities. I've yet to experience the peer to peer section of what they do, it's just because I don't have anyone or anything to turn to here where I live so my biggest thing to tell them is well it's an organization that really looks out for their patients.”

When asked what the Oley Foundation means to them one participant responded, “It’s so well informed that when I feel like I’m all alone in this that they have my back, that someone is there standing up for me.” Similarly, another participant stated:

What it means to me is just a having a great organization that actually advocates for individuals on parenteral or enteral nutrition. It provides a good deal of education, support and product information for individuals who are going through it to make their lives easier. And to be able to help them live the best that they can on it.

One consumer described using information from the Oley Foundation to lobby for continued Medicare coverage:

I’ve used my experiences to do a little lobbying. I’ve never been real political before until I got sick, it kind of changed my view on politics so I know I have faxed some information that I got from the Oley Foundation in a letter to my congressman . . . so I have faxed him two or three times.

When are participants introduced to Oley?

Participants in this study were introduced to the Oley Foundation at very different time points in relation to their experience with HPEN. Two participants found the organization while doing research before starting HEN. For example one participant explained, “So I did a Google search and they kept, they kept popping up. So I was looking around learning what the feed tube was about”. Other participants were introduced to the organization soon after beginning HPEN, “it was early on that I realized that the Oley Foundation was a specialist in my area and so I just went online and read everything I could.” Seven participants were introduced to the Oley Foundation years after beginning HPEN.

Well I didn’t know about the Oley Foundation, and I’ve been sick for three years, nobody said one thing to me about... “hey there is an organization for people who have to have supplemental nutrition.” I didn’t even know that existed until now

Two participants were introduced to the Oley Foundation when they began a new type of nutrition therapy, despite having been on some form of HPEN for years. One woman was doing research when she began HPN, “I believed I looked into it about two years ago. And I had, I had previously been on J-tube feedings and then I switched over to TPN and was doing some research. That’s when I came across Oley.” Some participants were introduced to the Foundation earlier in their experience with nutrition support but didn’t become involved until later on, “initially it was provided when I started tube feeding. But I didn’t really look into them much until about

probably ten months ago or a year ago because I was having a lot of trouble with the tube.”

How are participants introduced to the Oley Foundation?

Seven out of thirteen participants found the Oley Foundation on their own, either through search engines or other education/support organizations (Inspire and GPACT). For example, “I found them by myself actually. Just looking on Inspire.com and I found their group on there. Then I got on their website and found more information there.” One participant described finding the organization on her own and finding out later that her doctors and homecare agency were familiar with the organization but had never recommended it. “I think I Googled something one time. But I do know that my doctors in (large city) are associated with it and my homecare agency is associated with it.”

Medical professionals including a multidisciplinary nutrition support team, a wound care nurse, and dietitians introduced six of thirteen participants to the Oley Foundation. One participant who was introduced several decades after beginning HPN stated, “one of the nutrition support people that I’ve dealt with, forever, practically my whole life. She talked to me about it and asked if I’ve ever looked into so I finally did so that’s when it was introduced.”

Two participants were introduced in response to complications. “Actually it was through, what was it, a wound care nurse . . . She was helping with the tube and cause . . . my site was very irritated and she had gotten tips from the website actually”

A female HPN participant explained:

So when we got that bad news, they said there wouldn't be any medications available, that I was a candidate for intestinal transplant. . . . a lot of stuff happened in this appointment and the nutritionist at the clinic recommended the Foundation to me. One of the things that she said, or that the doctor said is that I wasn't alone in it, that there were other people like me.

“I wish I would have known about it sooner”

A dominant theme that emerged from discussions about how and when participants were introduced to Oley was that participants felt they would have benefited from finding out about the Oley Foundation sooner in their lives. One participant who grew up on HPN stated:

I would say it was something that I kind of wish I would have known about a little sooner in my life. Just dealing with the things that I've dealt with. Just cause I never really knew there were a whole lot of people out there who have it. And I've been dealing with this for the last.. for my whole life. So as far as the Oley Foundation is concerned I mean people like that I've dealt with parenteral nutrition. I mean I've been on it, I'm one of the longest patients that have been on it. I'm going on 30, 33 years. I just kind of wish I knew about it sooner just to have that kind of insight that other people are dealing with, just to . . . kind of help me out on my road. On my little journey if you will.

Another participant stated

Yeah, I didn't learn about the foundation until a year after I started . . . at least a year and a half. I wish I had learned about it much sooner when I'd gone on tube feeding. Because it was. . . it had stuff on how to deal with everything

from dealing with leaking from the tube site which has happened, to different types of tubes, to again the social aspect. So . . . everything is kind of discussed and even . . . again the social aspect and traveling and hanging with friends, and can you swim? I was a big swimmer, I didn't know if I could swim and you can. So everything is kind of addressed and I wish I had known about it much sooner.

Some consumers struggle as they adapt and transition to life with HPEN and Oley can help with that, as expressed by one participant

I think it should have, when I first got sick and had to start doing TPN at home, I think it should have been brought up in some sort of literature, like in dismissal instructions from the hospital. . . . what I think, and follow up calls, follow up. Because I think it would have, I mean I didn't find out about until 2 years after I'd already been on it. I think it should have been sooner, I think it would have helped me emotionally and physically.

When asked when the Oley Foundation should be introduced to a new consumer all participants said as soon as possible

I would say, introduce them beforehand. Like if they could know about it beforehand, before they actually start their feeds. That's when I would say to introduce it. So that way they kind of have a heads up about what is involved. That really helped me.

One participant recommended introducing the Foundation at two points.

I mean I suppose if the person is going on enteral or parenteral nutrition for the first time it would be probably best if they got the information maybe at two

points, one when the doctor is discussing the potential course of treatment with the patient so they can do research about whether this is appropriate from the patient perspective and then after some period of time after they've started the enteral or parenteral nutrition to have the in this case I'm saying doctor but the medical provider the person is speaking with again mention the Foundation that way they've got both before and after the treatment has started.

Most participants recommended that the organization be introduced by a clinician.

I think it should come from a doctor. I think that, or a homecare agency. I wish somebody would have informed me early on that it was there. I mean after I found out about it and asked around at doctor's offices and home care agency they were like "oh yeah we're involved in it blah blah blah". So it would have been nice, just like if you had cancer they would give you cancer sites' information.

Three participants expressed that an introduction to the Oley Foundation would be best if it came from a clinician, but weren't sure that that was possible.

. . . I think probably, it depends on where they start. Like if they start in the hospital I don't think hospitals would give out that information. But I mean that would be a great place, before they actually go they could . . . do some research.

Concerns about Social Media Sites

The overall discussion about the Oley Foundation was positive. Participants did however raise some concerns about social media sites like Inspire or Facebook.

Some participants believed that these sites can have an overwhelming amount of posts or posts that are discouraging.

One participant stated:

I don't use it that much, right now. The more people participate in such a community is good and bad because the more people there are there's more information to be exchanged but also there's more things to follow up on and more difficult, the more questions there are , to find the relevant information for oneself . So . . . I found it becoming a little bit too much information and I really haven't had any specific issues that I've needed to follow up on so I haven't really gone back to the site.

Another participant acknowledged this when he recommended the Oley Foundation to others:

But the things that I always caution them on is that some of the people there as far as within the Oley Foundation they have their attitudes with it in the discussions might be , I guess you could easily consider them a Debbie downer or something where they just seem they're always or their attitude isn't very positive. And so I caution those people that I have given it to them and said just be mindful of that . . . look for the positives out of it. You are always going to have these major downs in your life you're going to have these major downs that you have to deal with when you're going through this process. Don't ever lose sight of, it will get better. You just have to kind of get in this groove of how things are going to work out. And . . . you just need your own groove but don't ever take any of the things that people post or that people may say as a

downer. You don't know what they are dealing with. They could be dealing with something completely different. Just look for the positive in it and take those positives and go with it.

Similarities and Differences between HPN and HEN consumers

Similarities

Overall HPN and HEN consumers were very similar in the way in which they talked about their experience with the Oley Foundation. All major themes emerged in the analysis of the narratives from both groups. One example of a similarity between HEN and HPN participants is the idea that there is so much information that participants check in with the organization every day.

Male HEN participant

I would say that the Oley Foundation should be bookmarked on your web browser, so that every time you open your web browser if you have a feeding tube it should be the first page that comes up on your web browser because there is so much information. The Oley Foundation should be your partner.

Female HPN participant

The bottom line is, it's my go to source now. I am checking email every day, where before I was only checking it maybe a couple times a week. I'm checking it every day and going online to their website probably three times a week, just to gain more knowledge and information.

Differences

Participants had concerns that differed by type of therapy they receive. Half of the HEN participants expressed concern about insurance coverage. One consumer stated, “my biggest problem right now is that my insurance won’t cover me for a nutritionist consult.” Nearly all of the HPN participants brought up the topic of drug shortages. One consumer stated, “Probably the most difficult thing recently has been that because of the nationwide shortage of lipids, I haven’t had lipids in 6 weeks.” Content differences illustrate the role that the Oley Foundation plays in the lives of HEN and HPN participants. Half of the HEN group spoke about using the supply exchange while no one in the HPN group used that program. HPN participants spoke about using Oley to keep up to date on drug shortages.

The, definitely the emails, especially regarding the recalls. And the information that they put on the website regarding the recalls and even drug shortages.

Because drug shortages are impacting me directly. That's been a huge thing, that sucks more or less, because every time that happens I have an adjustment to my TPN. There’s definitely, it happens, and it takes me a little bit to get used to it. And I’m having to take different meds through my J-tube now because I can't get them in the IV bag because of the drug shortages. So the recalls and drug shortages for me has been significant.

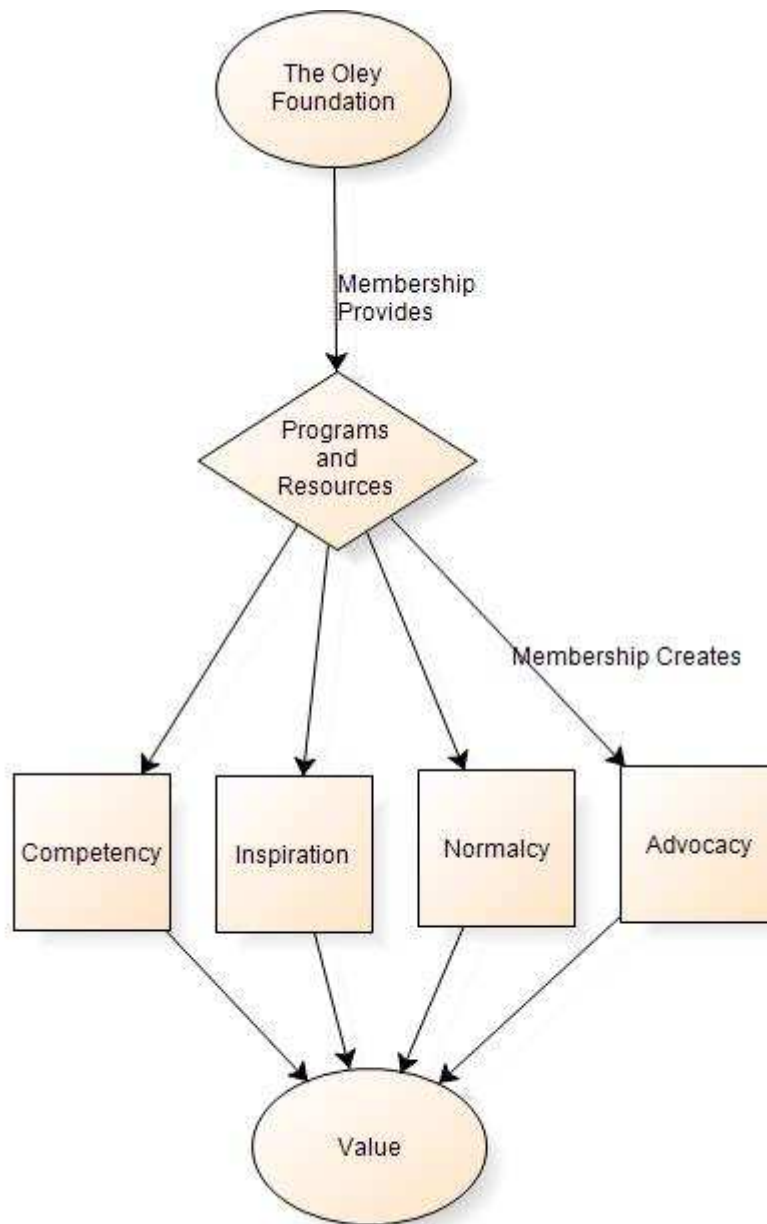
Discussion

The results of this study suggest that the value of the Oley Foundation lies in the competency, inspiration, normalcy, and advocacy gained from membership. In this study participants were introduced at a variety of points in time. More than half of participants found the organization on their own. A clear theme that emerged from the discussion of participant's introduction to organization was "I wish I knew about it sooner". These results are important because it deepens the understanding of how and why participants become involved in the Oley Foundation and what ways it could benefit new consumers.

Current literature has explored challenges that are experienced by HPEN consumers^{3,24,26}. The impact of these challenges and others on quality of life in HPEN consumers has been shown to be related to complications, isolation, need for lifestyle adaptations and discrepancies between expectations and reality^{4,6,7,24}. Studies have shown that HPEN consumers have unmet needs and may perceive things differently than clinicians. Education of consumers has shown to improve patient outcomes and competence in managing their own care although physicians are not always comfortable providing this education^{18,22,27}. The Oley Foundation has been shown to have an effect on health outcomes for HPEN consumers as well as providing support, education and mentors to help foster coping skills^{6,7}. Other support organizations have been shown to be valuable to participants by: increasing knowledge and confidence, providing peer support and empathy^{17,28}.

Figure 1 shows a visualization of the value perceived in membership in the Oley Foundation by participants in this study. The information and resources provided by the Oley Foundation through membership create competency among members. Educational resources gave members the tools and confidence they needed to manage their complex therapy. Consumers feel inspired by other members who are successfully integrating HPEN into their lives. Similarly, members are able to achieve normalcy in their own lives. Members appreciate the Foundation's advocacy on their behalf and use its resources to advocate for themselves and other consumers. Collectively these important themes relate to the perceived value of membership in the Oley Foundation.

Figure 2: A Conceptual Model of Value in Membership in the Oley Foundation



Programs and resources provided by the Oley Foundation serve a wide variety of functions; see Appendix E for a sample of the Foundation’s homepage. Participants took advantage of resources from print materials, like the complication chart, to online

forums for discussion on the social media sites. Educational resources have been shown to be valuable to members. Lasker et al. found that in a group for people with biliary cirrhosis members primarily looked for biomedical information ¹⁶. While this assessment is important it does not uncover the intangible, potentially un-vocalized benefits seen from this study. This search for knowledge along with “the wisdom of the common folk” gained through organizational involvement are important in gaining competency.

Munn-Giddings found that members of a support organization for caregivers also gained a sense of competence from membership which allowed them to communicate more effectively with health care professionals ¹⁷. This competence combined with improved communication may allow participants to manage their own care. Fex et. al. found that education, support and planning were important factors for people medically dependent on technology to have in order to manage their own care ¹⁸. This analysis also showed that the importance of living is an important factor in self-care.

In this study participants were inspired by others who were thriving on HPEN and subsequently inspired to live their own lives. White and Dorman reviewed several comprehensive online support organizations for people who were quitting smoking, had cancer, aids, Alzheimer’s disease, and those caring for people with Alzheimer disease. A common attribute of each organization was that they provided support and encouragement ¹⁹.

Normalcy gained from the organization was important to most participants in this study . The subtheme “I am not alone” compares to previous research that describe support organizations for people on HEN as providing a feeling of universality ⁷.

Research conducted on groups focused on ALS and hemophilia found that advocacy was an important function of a support organization ^{20,21}. . Participants in this study describe the Foundation as one that is “really there or the patient”.

A clear theme that emerged from the discussion of participant’s introduction to organization was “I wish I knew about it sooner”. While this theme did not directly relate to our initial research questions it is important because it deepens the understanding of how consumers feel about when and how they were introduced. No previous research has investigated when members learn about organizations. Madigan et. al conducted a study with general practioner’s in the United Kingdom (UK) and found them to believed that patients were not prepared when they were discharged from the hospital with feeding tubes and that they themselves were not well educated on the topic. While this was a small study in the UK, and does not represent healthcare in the United States, several participants in this study described using information from the Oley Foundation to educate their clinicians.

No research exists on how and when consumers are introduced to the Oley Foundation. The majority of participants in this study found the organization on their own. More research is needed to determine if this is representative of members as whole. The results from this study indicate the need for education and understanding regarding the Oley Foundation and similar organizations on the part of clinicians.

HPN and HEN consumers were similar in the way that they spoke about the Oley Foundation but differed in the major concerns they had regarding their nutrition therapy. HPN participants were concerned about national drug shortages while HEN participants were concerned about Medicare coverage. These are national concerns that likely affect many members.

Strengths

Strengths of this study include the in-depth telephone interview which allowed for confidentiality for participants and the opportunity for them to speak freely and honestly about their experiences with the Oley Foundation. The member check allowed for increased validity of the data and the high inter-rater reliability showed good validity and reliability of the coding scheme.

Limitations

The sampling for this study, by design, does not represent all members of the Oley Foundation. The participants were all HPEN dependent adults who had joined within the past two years. Results, therefore, do not necessarily reflect what would be valuable to a child or adolescent, families, caregiver, clinician members, or those who have been members for many years. Participants were predominately Caucasian and college educated; different ethnic groups or those who are less educated may perceive value differently. Only participants with internet and telephone access were eligible to participate which also provided selection bias for higher socio-economic status although this demographic was not collected.

Selection bias may have occurred, as participants self-selected and were interested in willing to participate. On one hand those with a complaint to voice may

have been more motivated to participate; on the other hand members with higher levels of satisfaction may have been more likely to choose to participate.

Investigator's biases, values and knowledge of the Oley Foundation may have influenced the interview process or analysis. Despite these limitations participants discussed their experiences with the Oley Foundation, both negative and positive, and data saturation was achieved.

Only eight out of thirteen participants contacted investigators and took part in follow up calls in response to the summaries each participant received.

Future research is needed to address if other groups value the same aspects of membership in the Oley Foundation. The ability for the results to be applied to other online education and support organizations could also be investigated.

Take Home Message

This study aimed to gain a deeper understanding of value in the Oley Foundation. The themes that represent value to the participants were competency, inspiration, normalcy, and advocacy. Participants in this study wished they had learned about the organization sooner, indicating that more could be done to introduce new consumers to the organization; for example educating clinicians and agencies about the Oley Foundation and how to introduce new consumers. A focus on what is valuable to consumers could improve the way consumers are introduced to the organization.

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Appendix A: Literature Review

Home Parenteral and Enteral Nutrition Consumers

Home nutrition support is a long-term therapy that provides nutrition intravenously (parenterally) or through the gastrointestinal tract (enterally) when a person is unable to consume or digest enough food to maintain or restore nutrition status and health. Home parenteral nutrition involves intravenous infusion of nutrients through a central venous catheter for people who are unable to digest/absorb nutrients through the gastrointestinal tract. Common diagnoses resulting in a need for HPN include but are not limited to: obstruction of the small bowel, intractable nausea or vomiting caused by chemotherapy or disease, or a disease that affects the absorptive capacity of the gastrointestinal tract ²⁵. An infusion company or home healthcare agency typically provides HPN to consumers.

Home enteral nutrition (HEN) involves the provision of nutrients through a nasogastric tube or a percutaneous or surgically placed tube in either the stomach or the small intestine. Common diagnoses resulting in a need for HEN include neurological dysfunction, gastrointestinal cancers, and motility disorders ¹. HEN supplies are often distributed directly to patients. HEN patient monitoring is often not perceived as important as HPN patient monitoring by physicians, and their input for care of HEN patients is not always reimbursed ¹.

Although there are no complete databases of home parenteral and enteral nutrition consumers, the American Society of Parenteral and Enteral Nutrition estimates that there are approximately 73,000 HEN consumers and 39,000 HPN

consumers in the US ^{1,2}. While the ability to provide nutrition through alternate routes is a life-saving therapy, it is not without its complications. Consumers of home parenteral and enteral nutrition (HPEN) have many physical and psycho-social factors influencing their quality of life.

Current literature has explored challenges that are experienced by HPEN consumers ^{3,24,26}. The impact of these challenges and others on quality of life in HPEN consumers has been shown to be related to complications, isolation, need for lifestyle adaptations and discrepancies between expectations and reality ^{4,6,7,24}. Studies have shown that HPEN consumers have unmet needs and may perceive things differently than clinicians. Education of consumers has shown to improve patient outcomes and competence in managing their own care although physicians are not always comfortable providing this education ^{18,22,27}. The Oley Foundation has been shown to have an effect on health outcomes for HPEN consumers as well as providing support, education and mentors to help foster coping skills ^{6,7}. Other support organizations have been shown to be valuable to participants by: increasing knowledge and confidence, providing peer support and empathy ^{17,28}.

Factors Influencing Quality of Life

Physical complications such as mechanical problems with equipment, infections, and intolerance issues impact consumers of HPEN ^{3,4}. Psycho-social factors include coping with medical diagnoses, being dependent on technology, the loss of the eating experience, reliance on others for care, low self-esteem, interference

with sexual function and the financial burden of nutrition support. All of these present a challenge to the HPEN consumer ^{4,5}.

Crosby and Duerksen conducted a prospective study of complications in HEN consumers ³. Eight patients who had recently been discharged on HEN were asked to complete a weekly diary that listed seventeen potential complications. Examples of complications listed include: leakage, infection, pain, and gastrointestinal distress. Diaries were collected for a mean of 10.5 months. The most common complications were stomal discharge, bleeding stoma and granulation tissue. Discharge was recorded as being continuous throughout the weeks 72% of the time, rather than intermittent. Throughout 10.5 months participants had a total of 43 unscheduled contacts with health care professionals regarding complications with their feeding tube. A limitation of this study was participant burden and subsequent small sample size. Despite the limitations, the length of time and variety of complications it investigated allowed for a greater understanding of what complications affect HEN consumers.

Huisman-de Waal et. al. conducted a retrospective study on complications associated with vascular access device (VAD) complications for 110 HPN patients using medical charts ²⁶. Seventy-five percent of patients also completed surveys which assess psycho-social problems. The survey addressed medication use, quality of life, social impairment, depression, fatigue, physical complaints, coping, self-efficacy, social support, sexual disorders and anxiety. Information on hospital admissions was provided through national computer registration of patient data. Seventy-six percent of participants experienced infectious complaints at some point during their HPN

treatment while 42% of patients experienced vascular occlusion. Approximately one third of patients experienced another complication such as accidental removal or tearing of catheters. This study found that patients without VAD-related complications had significantly less depression ($p=0.012$), fatigue ($p=0.004$) and social impairment ($p=0.004$) as well as a better quality of life ($p=0.029$) than those who did have complications. This further underlines the need to prevent VAD-related complications. This research shows that psycho-social concerns result from the underlying disease state may not be as influential as complications in regards to quality of life for HPN consumers.

Silver conducted 3 semi-structured in-depth interviews online over a 5 month period with six adults and three children (8-10 years old) who were HPN dependent and the mothers of the three HPN dependent children²⁴. Participants were recruited from an American Society of Parenteral and Enteral Nutrition (ASPEN) list-serv and the Oley foundation. They were asked 13 questions about fears and challenges of total parenteral nutrition (TPN), interactions with others, incorporation of food etc. A phenomenological technique was used to study the conscious experience of HPN dependency as experienced by the consumer²⁹. Themes that evolved from the analysis of the interviews were the need for affirmation of life, fear of infusion related complications, lifestyle adaptations, self-worth in relation to accepting physical limitations, isolation, and coping with restriction of food intake. The study showed how HPN-related issues affect consumers. This information identifies needs that may be unmet for HPN consumers. These data can be used by clinicians and support organizations to better address client necessities and improve the quality of care.

Quality of Life Assessment

With all of the concerns about physical and psychosocial complications of HPEN, research exploring the concept of quality of life for consumers has been important ^{4,30}.

Baxter et. al. developed a treatment specific quality of life questionnaire for HPEN consumers. The researchers identified quality of life issues through a review of the interview and semi-structured interviews with healthcare professionals and patients. A provisional questionnaire was developed including 57 items relating to general health, HPN side effects and emotional issues and some clinical questions for example, the absence or presence of a stoma. Scoring ranged from 0-100 with a high score signifying a high level of functioning and quality of life. Questionnaires were cognitively tested and translated into seven languages to allow for international field testing. The final questionnaire included 47 items ³¹. The survey had a high acceptability and compliance, reliability of each item was assessed with a Cronbach α coefficient considered acceptable at 0.7. Seventy percent of the scales scored over 0.7. This study highlights how difficult assessing quality of life in HPN consumers can be because of the variety of factors that are involved. The high compliance and acceptability show that HPN consumers are invested in quality of life research.

Winkler and colleagues conducted in-depth interviews of 24 adults living on HPN structured to explore health-related quality of life, technological dependence, and food intake in chronic illness as well as important personal issues related to quality of life and living with HPN ^{4,32}. Participants were self-recruited after learning about the

study from announcements sent to home PN programs, home infusion providers, and website and newsletter postings of the Oley Foundation. Participants were stratified based on length of time of HPN dependency. Content and phenomenological analyses were used for interpretation of the data. The overarching theme from the interviews was that HPN was a life-support or a nutritional safety net. Five sub-themes were the definition of quality of life as “enjoying life”, the benefits of PN outweighing the burden of technology, the symbolic meaning of food context, achieving normalcy and discrepancies between expectations and reality. Themes that emerged in relation to eating behaviors included hunger and thirst, strategies for dining in restaurants, a perception of wasting money on food that is not absorbed. Three patterns of eating that participants demonstrated were; eating for survival, eating for health benefits, and eating for socialization. This study looked at self-perceived and defined quality of life in HPN consumers and found that they rated their quality of life well. This shows that qualitative methods are important in determining what consumers experience and deem important or meaningful in assessment of their quality of life.

Successfully coping with one’s disease state and nutrition therapy is one way to improve quality of life. Thompson and colleagues conducted a qualitative study with 12 adult HEN consumers to determine how health care professionals can foster coping skills in others ⁷. Two in-depth semi-structured interviews were conducted (telephone, in person or written response) with each participant who perceived themselves as coping well, met criteria for resilience, and were HEN dependent for at least three months and resided at home. This study used grounded theory to allow for the development of theory from the data ⁹. The primary questions that were asked of

participants were “How did you learn to adapt, cope and ultimately thrive with home enteral nutrition?” and “How can health care providers empower home enteral nutrition consumers to cope more successfully and develop a more resilient lifestyle?” The themes that emerged were an overall concept of personal responsibility with five categories including accepting a new life condition, seeking and accepting support, taking charge of well-being, and maximizing independence and normality. These themes were used to make recommendations to help improve how healthcare professionals help their patients on HEN. Recommendations included promoting personal responsibility and self-management, encouraging problem and emotion focused coping strategies, allowing flexibility, practicing collaborative decision making, identifying and treating mental health issues, and referring patients to support groups. Support groups, such as the Oley Foundation, were described as providing feelings of “universality” from sharing a common experience, practical information, and role models for new HEN consumers.

Education of HPEN consumers

Early hospital readmission is a concern for patients who are not adequately prepared prior to discharge. Smith et. al. conducted a randomized placebo-controlled clinical trial to determine the efficacy of the Interactive Educational Videotaped Intervention aimed at preventing HPN complications and increasing patient-physician problem solving²⁷. Participants in the control group received standard care including education on HPN and a recommendation for the Oley Foundation. Participants in the intervention group received three stages of intervention focused on infection

prevention, depression prevention and partnership in problem solving. The intervention focused on problem solving utilized resources published by the Oley Foundation. The primary outcome was infection and the secondary outcomes were depression, problem solving, quality of life, and satisfaction with the intervention. The intervention was successful at six months with the experimental group having a significantly lower frequency of CR-BSI ($p=0.03$), reactive depression ($p=0.01$), and re-hospitalizations ($p=0.01$). There was also a greater use of problem solving techniques ($p=0.038$). At an 18 month follow up differences continued for fewer hospitalizations and CR-BSI but not use of problem solving techniques or decrease in reactive depression. This study shows that education is important in improving outcomes for HPN consumers. A limitation is the burden on the participants, requiring a commitment of 20 minutes per day.

Madigan et. al. conducted a qualitative study with general practitioners in the United Kingdom to explore the knowledge, attitude and skills related to enteral nutrition²². Investigators conducted in depth interviews with 25 general practitioners who had experience working with HEN patients. Common themes that emerged were patients had poor discharge information, practitioners felt inadequately trained, and there was poor communication between primary and secondary care. Practitioners also voiced concern regarding lack of resource. This study shows a disconnect from hospital to general practice and a lack of education and communication. While the findings of this study are important it was conducted in the United Kingdom and it is not clear if the same results would be seen in the United States.

Fex and colleagues conducted a qualitative study to describe the experiences of self-care in participants using advanced medical technology (long term oxygen therapy or dialysis) at home¹⁸. In depth telephone interviews were conducted with 10 participants and a phenomenological approach was used for data analysis. Factors that allowed participants to manage their own care were support from medical professionals and significant others, cognitive capacity and a positive attitude towards life. Themes that emerged from discussion of self care were the importance of living healthy, planning for expected and unexpected complications, adjusting to technology, learning as a process, feeling tied up (for those on respiratory therapies) and feeling free (for those on dialysis) and having influence on the home environment. This study shows that support and education and planning can make self-care possible for people dependent on medical technology.

A Support Organization for HPEN Consumers

The Oley Foundation is a non-profit organization that provides up to date educational materials and social support for consumers of HPEN at no cost. The organization was founded in 1983 by Dr. Lyn Howard and Clarence Oldenberg, a HPN patient, in order to share information and support throughout the HPEN community. Educational topics include: current research, management of HPEN related complications, and practical topics such as travel tips. Oley provides social support through a toll free hot-line, social media groups on Inspire.com and Facebook, support group coordination, and regional and national conferences. By “informing,

connecting and supporting,” Oley hopes to improve quality of life for all consumers of HEN and HPN ⁵.

Smith and colleagues conducted a case controlled study looking at whether affiliation with a national support and educational organization (Oley Foundation) improved outcomes for consumers of HPN ⁶. Participants were recruited in two groups, the first from large academic centered medical programs (n=95) and the second from smaller community programs (n=121). Each group had participants who were affiliated with the Oley Foundation and matched case controls who were not affiliated with an education or support group. The case controls were matched for diagnosis, duration of HPN, gender and age. The groups were assessed for quality of life, reactive depression, and catheter-related bloodstream infections using validated questionnaires and physician's records. Participants that were affiliated with the Oley Foundation had better outcomes independent of program size with significantly higher quality of life, less reactive depression, and a decreased incidence of catheter-related bloodstream infections. This study shows an effect between membership in the Oley Foundation and improved outcomes for consumers of HPN. However, the study did not explain which characteristics of the organization lead to member benefit.

Other Support Organizations

One study that looked at what members in a social support organization gained from their involvement was conducted by Munn-Giddings and McVicar ¹⁷. A qualitative case study was used to explore why carers (defined as a person who cares for a relative, partner, friend or child with a disability, illness, or frailty) join and stay

in self-help support groups and what they feel they gain from the groups. Two self help groups were selected; one group was started by carers and the other group was initiated by a professional. Semi-structured interviews were conducted with founding members of each group as well as 15 active members. The three core themes were motivation for joining the group, personal gains from attending the group and contrasting self-help groups with professional services. The main motivator for joining the groups was a belief that there was something unique to gain from being with others in similar situations. The themes related to the value of the group to the participants were empathy, emotional coping, experiential knowledge, and peer support. Carers voiced concerns with professional help because they felt there was a lack of appreciation of the breadth of their caring responsibilities. Some participants expressed that membership in the group allowed them to feel more competent and able to communicate efficiently with professionals. This study shows that support from peers is valuable to carers because they gain empathy, emotional coping, experiential knowledge, and peer support. It also shows that group membership can increase confidence in skills and knowledge which allowed carers to communicate with professionals.

Many support organizations are run over the internet. One benefit of online support groups include asynchronous communication, the ability to respond to gain access and communicate whenever is most convenient ¹⁹. Other benefits include: an absence of barriers such as mobility or communication challenges caused by disease processes, and anonymity which allows for the discussion of potentially embarrassing topics.

Lasker and colleagues conducted a qualitative study on an internet-based group for people with biliary cirrhosis, a rare autoimmune disease of the liver²⁸. The data were collected by monitoring the organization's listserv for two months. The objectives of this study were to identify the issues with the greatest importance to those posting, compare frequency and content of posts by people at different stages of disease, and to identify how people with biliary cirrhosis represent psycho-social challenges identified in the literature as key elements of the experience of chronic disease. A content analysis was conducted using a coding system with three major categories (biomedical, socio-emotional and systems/organization) each containing twelve codes. Two-hundred seventy-five people posted 710 messages throughout the two month period. Each post was independently reviewed by two coders with 95% agreement. Demographic data was collected from signatures at the bottom of most posts including name, age, state, and year of diagnosis. The population was predominately female (95.6%) The dominant theme from all of the posts was biomedical topics which was unlike past research suggesting that women would be more likely to seek socio-emotional support. A motivator for participating in the listserv was that posters felt that their medical symptoms were not understood or acknowledged by others. While there were posts relating to stigma, uncertainty and role and identity change they were not as common as biomedical posts. Two suggested reasons for this were that the coding scheme was not sensitive enough to capture them or that posters feel that the listserv is not the forum to discuss such issues. This study captures what is relevant to participant's conversation in an online community for

people with biliary cirrhosis but does not analyze how the participants perceive the community.

Justification of the Study

While research shows that support organizations such as the Oley Foundation are valuable in terms of positive outcomes, no researchers have investigated what aspects of organizations are valued most by consumers. This study analyzed how consumers of HPEN perceived their introduction to the Oley Foundation and which programs and resources impacted them the most. Qualitative methods were used to gain a deeper understanding of what aspects of organizational involvement had the greatest influence on consumers' lives.

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Appendix B



Lifespan

Research Protection Office
Office of Research Administration
593 Eddy Street
Providence, RI 02903
Tel 401 444-6246
Fax 401 444-7960

E. P. Bradley Hospital
Rhode Island Hospital
The Miriam Hospital
Newport Hospital

DATE: December 17, 2012

TO: Marion Winkler, PhD

FROM: Patricia E. Houser, R.N., M.S.J.
Director, Research Protection Office

SUBJECT: **HUMAN SUBJECTS PROTECTION APPROVAL of New Project**
FWA-00001230, 00003538 IRB Registration #: 0000396, 00004624

CMTT/PROJ: 412712

TITLE: [348340-1, 348340-2 & 348340-5] A Qualitative Study of the Perceived Value of Membership in the Oley Foundation by Home Parenteral and Enteral Nutrition Consumers

Your research project was reviewed and approved on October 22, 2012. Requested IRB revisions were received and accepted on December 6, 2012. This research has been approved as meeting the standards for the protection of humans per 45CFR46/21CFR56 by the Lifespan - Rhode Island Hospital IRB 2. This institution is in compliance with the ICH GCP as they correspond to the FDA/DHHS regulations. This review and approval are applicable for RIH.

This notification CONSTITUTES AUTHORITY FOR ACTIVATION of this application.

It is the responsibility of the principal investigator to ensure that the study is conducted as approved by the IRB. All protocol modifications/changes must be approved by the IRB before any changes are implemented except when necessary to eliminate immediate hazards to subjects.

If written informed consent is required for this study: The newly stamped consents are included with this letter. Please review these informed consents to be sure you have received all the documents necessary to conduct this study. Please be sure all informed consents you submitted for approval, specimen banking forms and ads if applicable, are included and stamped with the approval and expiration dates. These newly stamped informed consents and other documents are to be used immediately for this study and supersede any previously issued documents, if applicable.

You are required by Federal regulations and Hospital policy to immediately report any unanticipated problems, untoward effects or reactions, serious side effects and/or deaths of subjects involved and related to this project to the IRB through the Research Protection Office.

IRB approval for this project expires on October 21, 2013. If you wish to continue your research after this date you are required to submit a continuation report (CR) prior to expiration of approval. A reminder notice will be sent approximately 30 days before the continuation report is due. The CR must be reviewed

THE
UNIVERSITY
OF RHODE ISLAND
DIVISION OF RESEARCH
AND ECONOMIC
DEVELOPMENT

OFFICE OF RESEARCH COMPLIANCE
70 Lower College Road, Suite 2, Kingston, RI 02881 USA
p: 401.874.4328 f: 401.874.4814 uri.edu/research/iro/compliance



DATE: January 2, 2013

TO: Geoffrey Greene, PhD
FROM: University of Rhode Island IRB

STUDY TITLE: [370482-2] A Qualitative Study of the Perceived Value of Membership in the
Oley Foundation by Home Parenteral and Enteral Nutrition Consumers

IRB REFERENCE #: HU1213-058

SUBMISSION TYPE: Revision

ACTION: APPROVED

APPROVAL DATE: January 2, 2013

EXPIRATION DATE: January 1, 2014

REVIEW TYPE: Expedited Review

REVIEW CATEGORY: Expedited review category # 7

Thank you for your submission of Revision materials for this research study. University of Rhode Island IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulation.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All SERIOUS and UNEXPECTED adverse events must be reported to this office. Please use the appropriate adverse event forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office.

Please note that all research records must be retained for a minimum of three years.

Based on the risks, this project requires Continuing Review by this office by January 1, 2014. Please use the appropriate renewal forms for this procedure.

If you have any questions, please contact us by email at compliance@ds.uri.edu. Please include your study title and reference number in all correspondence with this office.

Please remember that informed consent is a process beginning with a description of the study and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. Federal



Joan Bishop, Executive Director
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July 30, 2012

Katelyn Chopy
Graduate Student
c/o Marion Winkler PhD, RD, LDN, CNSC
Rhode Island Hospital
Nutritional Support Service
593 Eddy Street, NAB 218
Providence, RI 02903

Dear Katelyn,

This letter provides confirmation of The Oley Foundation's support of your research, "A Qualitative Study of the Perceived Value of Membership in the Oley Foundation by Home Parenteral and Enteral Nutrition Consumers". We understand that this research will be conducted in partial fulfillment of the Master in Science degree at the University of Rhode Island, under the mentorship of Dr. Marion Winkler, Surgical Nutrition Specialist, at Rhode Island Hospital.

Our Scientific Committee has reviewed the study. Once you receive IRB approval from Rhode Island Hospital and the University of Rhode Island, we will post the approved announcement recruiting for your study in the *Lifeline Letter* and on the Oley website. In addition, we will send an e-mail blast to members who have joined The Oley Foundation within the past 2 years, to target your defined study population.

We look forward to your results and findings.

Sincerely,

Joan Bishop
Executive Director

Appendix C

Recruitment Statement for Email Blast by The Oley Foundation

Oley Members Needed for Research Study

HPEN consumers are needed for a research study to discuss, by telephone, their involvement in The Oley Foundation and their experiences with home parenteral/ enteral nutrition. To be eligible you must receive home parenteral or enteral nutrition, have joined The Oley Foundation in the past two years, be willing to participate in a 60 minute telephone interview with one 15 minute follow up call, be over 18 years old, live in the United States, have an email address and telephone and speak English. All information will remain confidential. Interviews will be analyzed and summarized. Participants' identities will be protected. If you wish to participate please email University of Rhode Island graduate student, Katelyn Chopy, at oleystudy@etal.uri.edu and include your name, telephone number with area code and best time to reach you.

This research is being conducted in collaboration with Marion Winkler PhD, RD, LDN,
CNSC of Rhode Island Hospital/ Lifespan (401-444-4276)

IRB Approval: 10/22/2012
IRB Accepted: 12/6/2012
IRB Expiration: 10/21/2013

IRB Approval:	10/22/2012
IRB Accepted:	12/6/2012
IRB Expiration:	10/21/2013

Volunteers Wanted for Research Study

To participate in telephone interviews lasting about 1 hour with one 15 minute follow up phone call.

The purpose of this research study is to learn more about the aspects of membership in the Oley Foundation that are of most value to home parenteral and enteral nutrition consumers.

To Be Eligible You Must:

- Receive home parenteral or enteral nutrition.
- Have joined The Oley Foundation in the past two years.
- Be willing to speak about your experiences with HPEN and your involvement with The Oley Foundation.
 - Be over 18 years old
 - Live in the United States
 - Have an email address and telephone
 - Speak English

Confidentiality of all information will be maintained

For more information or to indicate your interest in participating in the study Email URI Graduate Student Katelyn Chopy at olevstudy@etal.uri.edu and include name, telephone number with area code, and best time to reach you.

This research is being conducted in collaboration with Marion Winkler PhD, RD, LDN, CNSC of Rhode Island Hospital/ Lifespan (401-444-4276)

Appendix D

Interview Guide

Introduction-
Hello,

My name is Katelyn. I am a graduate student and dietetic intern at the University of Rhode Island. I am conducting these interviews as part of a research project aimed at better understanding how membership in education, outreach and networking organizations, such as the Oley Foundation, impacts its members. I appreciate the time you've set aside to speak with me about your experiences with the Oley Foundation and living with nutrition support.

Before we begin, I want to review a few things with you:

- Your participation in this interview is completely voluntary; you may choose not to participate.
- If there are any questions you do not wish to answer, just let me know and we can skip it.
- You can stop the interview at any time.
- Each interview should take about one hour or longer depending on how much you want to speak about.
- Our conversation will be kept completely confidential.
- I am in a private office and will be using a speakerphone. No one else will be in the room with me.
- If you agree, our conversation will be tape-recorded in order to document your exact words. If you mention any personal information, names, home care companies, or hospitals the names will be changed when the tapes are transcribed so that you cannot be identified. The tapes will be destroyed at the end of this project. Transcripts will be numbered and will not contain your name or any identifying information.
- There is no risk to you by answering these questions. There is no direct benefit to you. It is hoped that the information from the study will lead to a better understanding of how organizations like Oley can benefit HPEN consumers.
- I will send you a summary of our interview and we will schedule a follow-up call to ensure that my interpretation of what you said is correct.
- Your comments will be combined with other study participants when the results are analyzed.

- Nothing you tell me will be presented or published in a way that someone could identify you. I may use some quotes anonymously in written articles or presentations.
- This research is being conducted in collaboration with Marion Winkler PhD, RD, LDN, CNSC of Rhode Island Hospital/ Lifespan (401-444-4276) and is funded by the Department of Surgery/Nutritional Support Service.
- If you have other concerns about this study or if you have questions about your rights as a research participant you may contact the University of Rhode Island's Vice President for Research, 70 Lower College Road, Suite 2, URI, Kingston, RI, (401) 874-4328 or the Institution Review Board at Rhode Island Hospital ([401-444-6246](tel:401-444-6246)).
 - Do you have any questions about the information we discussed?
 - I will be turning the tape recorder on now. Do I have your permission to tape this conversation?
 - Do I have your permission to contact you in the future for a follow up?

1. Do you receive parenteral or enteral nutrition?

2. Could you please describe your involvement with the Oley Foundation.

What has this involvement meant to you?

Probes-

How were you introduced to Oley, by whom and when?

How would you describe Oley to someone new to HPEN?

How would you describe your level of participation in Oley?

What programs and resources do they provide?

Are you aware of any (newsletter/educational materials/ conferences/ social supports)?

Have you utilized any of these programs/resources?

How has the organization impacted you?

What programs and resources of the organization have helped you the most?

What would you change about Oley?

Do you belong to any other educational or support organizations?

3. What has your experience living with home parenteral/ enteral nutrition been like?
How has your involvement in Oley influenced this experience?

Probes-

Who helps you with your HPEN procedures and care?

What challenges have you experienced living with nutrition support?

How has nutrition support positively or negatively influenced your life?

What programs/resources does Oley offer that have changed your home PN/EN experience?

4. Given your experiences living with HPEN and as a member of the Oley Foundation what recommendations would you make to new consumers of HPEN?

Probes-

What form of introduction was best for you?

Personal by clinician, exploring on their own, brochure in welcome packet, social media network, other.

At what point in the transition to home should a clinician introduce the Oley Foundation to a new consumer and how should this discussion be approached?

What should be included when Oley is introduced?

5. Could you summarize, in a few sentences, what the Oley Foundation means to you?

Demographics:

What medical condition led to your need for home parenteral/enteral nutrition?

How long have you been on HPEN (what year did you start?/how old were you?)

What is your age today?

What is your gender?

How would you best describe your race/ethnicity?

How many people live in your home with you?

What state do you live in?

Are you currently employed full or part time?

Are you enrolled in school?

Is there anything else you wish to discuss that we have not talked about?

Thank you for time and participation in this study.

Appendix E

5/21/13

Oley Foundation Home Page

[Home](#) / [Resources](#) / [Meet Patients](#) / [Conferences](#) / [NY HPN](#) / [Research](#) / [Equipment/Supplies](#)
[Travel Tips](#) / [About Oley](#) / [Tell Others](#) / [FAQ](#) / [Links](#) / [Contact](#) / [Forum](#) / [Corporate Info](#) / [Donate](#)

Enriches the lives of those requiring home IV & tube feeding through education, outreach, & networking



Carol uses courage, strength, energy, and attitude to get through those days when "it is difficult even getting out of bed." The best therapy for her is caring for horses.... [more>>](#)

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[Shortage From FDA to A Nurse Shortage](#) (5/6/13)

[Update from ASPEN](#) (4/24/13)

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Tube Feeding Survey



... IVTherapist Survey Closing Soon!

[Most Recent News letter](#) (4/3/13)

[Media Coverage - TV, Radio, Press](#) (5/9/13)

[Volunteers Needed for Research Study](#) (4/30/13)

[FDA Approves Treatment for Adult SBS Patients](#)

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Advocacy

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